Consumers in Health Care: Creating Decision-Support Tools That Work

Prepared for

California HealthCare Foundation

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Shaller Consulting

Acknowledgments

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About the Foundation

The **California HealthCare Foundation**, based in Oakland, is an independent philanthropy committed to improving California's health care delivery and financing systems. Formed in 1996, our goal is to ensure that all Californians have access to affordable, quality health care. For more information about CHCF, visit us online at www.chcf.org.

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I. Executive Summary

Americans are being required to take an active role in decisions concerning their health care, especially related to selection of health plans and providers. This report examines the range of decision-support tools available to help make those decisions, summarizes evidence regarding their use and effectiveness, and offers possible strategies for overcoming some of the barriers to their more widespread and effective use.

Range of Health Care Decision-Support Tools

There has been a recent proliferation of tools related to the selection of health plans, as well as tools to assist with choice of doctors, hospitals, and other health care providers. These range from the health care "report cards" that present comparative performance information on different health plans and providers, to provider directories that offer detailed information on a physician's background and practice. There are also tools related to specific care and treatment choices, aimed at helping patients answer questions about available treatment options. These often include patient decision aids that can be used alone or in combination with personal counseling by clinicians or other professionals to understand alternatives, to consider the probability of different outcomes, and to clarify the values patients bring to issues of benefits and risks.

The functions served by these tools include framing the decision context for the consumer, providing essential data and background information, sorting and processing complex information, clarifying a patient's values and preferences, and providing structured guidance through the process of decision-making. Formats, too, range widely and include print publications, videos and CD-ROMs, audio-guided workbooks, Web sites, and personal counseling.

Evidence Regarding Use and Impact

While a broad range of decision-support tools exists, evidence regarding their use and effectiveness is quite limited. And the results of studies that do exist are somewhat mixed. For example, the use of comparative reports on health care quality has grown rapidly in recent years, but relatively few evaluations have been conducted that might allow findings to be extrapolated broadly.

Experimental studies generally find that report cards can positively influence consumer decision-making when the information is easily understood. But the studies that have examined the effect of report cards on actual consumer behavior have produced conflicting results: Some have found that health care quality information influences consumer decisions, while others have concluded that it has no significant effect.

With the growth of consumer-directed health plans and the corresponding increase in plan types consumers have to choose from, the use of decisionsupport tools focused on health plan choice is rising. Decision tools related to health plan choice have been shown to improve users' knowledge, satisfaction with the decision process, likelihood of considering alternatives to current plans, and selection of plans that best meet consumers' personal needs and preferences.

The availability of information for patients regarding their choice among specific care and treatment options is also expanding, with many tools now available on the Internet. Controlled trials have shown that such decision aids improve patient knowledge regarding options, enhance realistic expectations about various alternatives, reduce patient frustration with the decision-making process, and stimulate people to take an active role in decision-making.

Key Barriers to Effective Use

Although the availability of decision-support tools is increasing, a number of barriers impede their widespread and effective use by health care consumers and providers. Many of these barriers arise from the design, content, format, and dissemination of the tools themselves, including:

- Lack of relevant content, such as comparative information on individual doctors and on the cost of health care services.
- Poor tool design and confusing presentation of complex information.

 Limited consumer awareness of information on physicians and hospitals, health plan decisionsupport tools, and other patient decision aids.

Other barriers to effective use are related to the characteristics of the intended audience or to the structure of the health care system more broadly, such as:

- Low levels of literacy, especially among the elderly and the poor.
- Lack of trust in the source of decision-support including employers, health plans, and government agencies.
- Lack of online access to Web-based tools, particularly among the elderly and the poor.
- Health care practitioners' lack of time to engage in informed decision-support with patients, practitioners' lack of training in decisionsupport skills, and the absence of reimbursement incentives that reward practitioners for engaging in decision support.

Strategies for Promoting More Effective Use

This report discusses a number of strategies for addressing some of the tool design and dissemination barriers noted above.

Consider the decision context and audience. Tool developers need to understand the environment in which health care decisions are being made, as well as the needs and preferences of potential users of these tools. The nature, frequency, and complexity of the decision should influence the kind of information provided and the way it is delivered. The characteristics of users should also influence both presentation strategies and dissemination

Test early and frequently. Consumer testing particularly focus groups and individual interviews with potential users—can play a major role in ensuring that a decision-support tool satisfies a real need.

channels.

Craft appropriate content. The appropriate content for any particular tool will vary according to many factors, including the decision being supported and the characteristics of the intended audience.

Decision-support tools should provide a clear and concise explanation of the purpose and use of the tool; a compelling motivational message that frames the value of the tool; references to familiar information with which users can readily identify; and clear explanations of complicated or technical concepts and terms.

Make complex information accessible. Tool developers need to present sometimes complex information in ways that allow users to easily access relevant material, understand its key messages and implications, and make comparisons of appropriate options. Strategies for doing this include:

- Breaking down decisions into discrete steps;
- Simplifying difficult tradeoffs (for example, by clarifying relationships between cost and quality;
- Making navigation easy, in both print and Webbased media, through the use of simple figures, graphics, and headings;
- Making information easy to evaluate, through the use of performance ranking, symbols, summary tables, color coding, and narrative stories;
- Layering information, by locating more general information early (in a written tool) or at higher levels (in the structure of a Web-based tool); and
- Using easily understood categories or frameworks to convey complex information.

Select an appropriate medium. For example, relatively simple choices are usually best supported through easy-to-use, low-tech media, such as printed information, worksheets, or videos (all of which are also more accessible to users without online access or skills). More complex choices, where tradeoffs are less clear, may be better served by interactive CD-ROMs or Web sites. Personal counseling, such as

training clinicians in the requisite skills and using third-party decision counselors, is also useful.

Maximize awareness. Strategies for successful marketing and distribution include promoting tools through a comprehensive communications strategy. It is also important to build credibility and trust with users by creating or associating with a brand image that makes the tool recognizable and acceptable, or leveraging existing relationships with trusted advisors, including personal physicians and organizations such as religious institutions and cultural associations.

Make tools available when needed. Provide consumers with access to the tool at the point when they will actually be making a decision. There are certain "teachable moments" when consumers are most likely to need support, such as when they choose a health plan, new physician or group practice, become eligible for Medicare, are diagnosed with a serious medical condition, or require a major procedure or new medication.

II. Introduction

Americans are taking an increasingly active role in decisions concerning their health care. And as the number and complexity of these decisions expand—from care and treatment choices to selection of health plans, hospitals, doctors, and other providers—new information and tools are being developed to support consumers in their health care decision-making.

Certain forces in the health care environment are requiring consumers to become more actively involved in decisions related to their health care, while other factors are permitting and encouraging consumers to inform and empower themselves regarding such decisions. Following years of declining choice in health plan options, the emergence of consumer-directed health plans has led to a growing array of decisions that consumers must make related to benefit options, including premium levels, deductibles, copayments and coinsurance rates, as well as varying levels of choice in provider networks. Once enrolled in a health plan, consumers must select specific providers for care, including doctors, hospitals, and specialists. Depending on individual circumstances, potential decisions abound regarding options for treatment of specific illnesses and conditions. And the growing culture of involvement has led many patients to insist on a more prominent role in decisions related to their care.

This report examines the range of decision-support tools currently available, summarizes evidence regarding their use and effectiveness, and offers a number of strategies for overcoming some of the barriers to their more widespread and effective use.

The audience for this report includes not only those charged with developing decision-support tools but also those responsible for offering these tools to consumers, such as public and private employers, Medicare, state Medicaid programs, and health plans. Policymakers and foundations with an interest in promoting decision-support tools also may find the report of interest.

This report is the second in a series on consumer decision-making in health care. The first report, Consumers in Health Care: The Burden of Choice, described the changing environment for health care decision-making and summarized the evidence on how

consumers make decisions, drawing from decision research, advertising, and social marketing. It concluded with a brief summary of the implications of this evidence for developers of information and tools intended to support sound consumer health care decisions. This second report builds on the groundwork laid in the first, by focusing specifically on decision-support tools and what can be done to improve their effectiveness.

III. Overview of Decision-Support Tools

THE LANDSCAPE OF DECISION-SUPPORT TOOLS IS diverse, with several types of tools serving a number of interrelated functions and being offered in a variety of forms. This section provides a summary view of that landscape, emphasizing the major elements of tool function, design, and format.

Functions of Decision-Support Tools

The primary role of decision-support tools is to help people make informed decisions by providing and managing information, clarifying preferences, and presenting the tradeoffs involved in various possible choices.² Within that primary role, some of the major functions of decision-support tools include:3

- **Framing the decision.** Many consumers find it difficult to know even how to begin thinking about an important health care decision. One important function of many decision-support tools is to provide guidance concerning which criteria are important in making the decision. For example, one approach to framing the selection of a health plan is to suggest that quality factors are important in addition to cost, and that disregarding quality could lead to adverse personal health outcomes. Tools that help frame a decision can do so either by providing the user with a set of criteria or by helping users to generate their own. Framing can also serve to broaden the kinds of factors the consumer considers when making a decision.
- Providing information in an unbiased way. Decision aids can present information in an unbiased and objective way, in contrast to information provided by parties with vested interests (such as providers or suppliers interested in steering consumers toward certain treatments or sites of care).
- Storing, sorting, and processing information. Some decisions are difficult for consumers due to the vast amount of potentially relevant information available. Decision-support tools help the decision-maker winnow a large set of options and thereby reduce the number of different information inputs to be factored into a decision.
- **Clarifying preferences.** Some decision-support tools assist the user to explicitly rate or rank available options based on personal preferences. This assistance is especially valuable for the many

people who have difficulty determining what their true preferences are. Indeed, many decisionmakers change or refine their preferences as the implications of ratings are made more clear.

■ **Guiding choices.** This function involves combining identified preferences with information about the available choices. Decisionmakers are shown how to use their preferences to weight or narrow their options. Various methods are available for guiding users step-by-step through possible options, from paper worksheets and checklists to interactive computer technology.

Not all tools include these functions; the particular functions included in a given tool depend on its purpose and the type of decision being supported. For example, tools that help people choose among options to treat a medical problem may stress functions that help users clarify the features that matter most to them. The role of personal preferences has been shown to be especially important in choosing among options for treating conditions such as breast cancer and prostate cancer, where different treatment options carry very different lifestyle implications. Some tools, such as comparative report cards on health plan performance, tend to be quite limited in the functions they include; many report cards provide only unmediated information, often through complex data displays, and therefore ignore most of the other possible functions of decision-support tools, as discussed above.

Decision-Support Tools Come in Many Formats

The various functions of decision-support tools can be accomplished through a variety of formats and media:

- Printed booklets and worksheets. Used in numerous applications such as health plan report cards, provider directories, benefits comparison materials, and self-care guides.
- Computer applications. Either online or off (CD-ROMs), such as online plan enrollment tools, Web-based provider directories (many of which now offer personal profiles of providers and advanced search functions), and online consumer tools regarding care and treatment options related to specific conditions.
- Audio and videotapes. Present information on treatment options and instruct patients in self-management skills, many in the context of disease management or shared decision-making programs.
- Personal counseling or coaching from a trained advisor. Include "health coaches" working with chronically ill patients, communitybased outreach workers assisting public program (e.g., Medicare and Medicaid) beneficiaries in understanding benefit options, information hotlines in employer benefits offices, and training seminars at the work site or in community centers.

Types of Health Care Decisions and Support Tools

This section sets out both the types of decisions most commonly addressed by consumer-support tools and the specific kinds of tools that have emerged to serve these purposes.

Decision-Support Tools for Plan and **Provider Choice**

A variety of decision-support tools have been developed to support consumers in making health plan enrollment choices, including decisions among various plan types and levels of costs and benefits. At the simple end of the spectrum, a health plan decision-support tool for consumers might consist of a printed table displaying comparative information on the benefits and premiums of different health plans offered by an employer during open enrollment. A slightly more advanced version of such a health plan decision-support tool might provide a personal worksheet that helps the user identify and compare specific features of the available plan options. Such worksheets have been shown to help users sort through options and select a plan with the most desired features.

A far more sophisticated version might be a computer-based interactive application on the Web, allowing the user to predict their health care use for the coming year and thereby to estimate outof-pocket costs across available plan and product options. Such Web-based tools are becoming increasingly common, as insurance companies and employers seek to assist beneficiaries to become more cost-conscious and selective in their health care decisions. Many of these tools include information on health plan clinical quality performance and member experience, along with a list of providers affiliated with each plan. In order to facilitate plan selection, users of these tools can create customized reports that rank plan attributes in order of personal preference.

Once enrolled in a health plan, consumers must select specific health care providers for care, including doctors and hospitals. To find a provider within the plan network, health plan members can rely on a printed directory that lists which doctors, hospitals, and other providers are available to them. These directories typically include the name and contact information for each provider, often organized by location and type of practice and speciality. Some also include the doctor's hospital affiliation, office hours, and languages spoken. Hospitals affiliated with plans are also listed.

Tools for organizing and publishing provider directories have evolved rapidly. While printed

Consumer Ratings of Health Care Decision Complexity According to a recent Forrester Research poll, consumers consider choosing a health plan and type of coverage as among the most complex health care decisions they make.⁴ Selecting a health plan or coverage type was reported as equally difficult for consumers as choosing among treatment options, and considerably more difficult than choosing among medications, picking a primary care physician, and selecting a hospital. "How complex, if at all, do you feel the following health-related decisions are to make?" Percent of respondents rating the decision as complex: 65% Selecting a health plan Choosing a type of health coverage (e.g., HMO vs. PPO) 65% Choosing between different medical treatment options Comparing different prescription medications 57% 51% Selecting a primary care physician Choosing between prescription options (e.g., brand vs. generic) 45% 42% Selecting a hospital

directories are still common, many health plans have launched Web-based directories to provide members with access to information online. The content of more sophisticated online directories now includes such information as personal profiles of providers (background and training, board certification, practice philosophies, photographs), as well as quality and performance ratings (based on patient survey data, clinical data, or both). Webbased directories allow consumers to search for providers by benefit plan, location, specialty, and hospital affiliation. They can also include direct links to provider Web sites, thereby making it easier for patients to obtain detailed information on physician practices.

Increasingly, decision-support tools for evaluating and selecting health care providers are being made available directly to consumers, whether enrolled in a health plan or not. These online search tools allow users to look up specific providers, for example, hospitals, nursing homes, and physicians, by location (city or Zip Code), medical specialty, gender, and other characteristics, and compare them by other selected features such as years in practice, board certification, and specific quality measures (such as consumer ratings and clinical indicators). Some tools charge a fee for access while others do not, and some health plans have purchased access to pay-per-view sites as a service to their members.

Decision-Support Tools for Care and Treatment Choice

Online tools to support consumers in learning about care and treatment options related to specific conditions or health-related issues are gaining attention. According to a 2004 poll by the Pew Internet and American Life Project, 80 percent of Internet users have looked online for information on at least one of 16 health topics, "with increased interest since 2002 in diet, fitness, drugs, health insurance, experimental treatments, and particular doctors and hospitals."5 In 2005, Consumers Union, one of the most trusted names in consumer information, launched a new subscription-based

Consumer Reports MedicalGuide.org Web site, offering consumers \$5 per month access to "independent, trustworthy information on best treatments and prescription drugs".6 Among thousands of Web sites providing various levels and quality of information on treatment options, healthy lifestyles, and specific health care providers are popular sites such as WebMD, MayoClinic.com, Aetna's InteliHealth directory of health Web sites, and www.health.gov, the Federal government's portal to Web sites of health agencies and initiatives. The National Library of Medicine now sponsors a free search engine called Medline Plus: Trusted Health Information For You (www.medlineplus.gov), which offers links to sites with information on hundreds of health topics, drugs, and health-related resources for the general public.

In addition to online information tools, other forms of consumer decision-support regarding care and treatment are gaining attention. These include CD-ROMs and videos that present treatment options and teach self-management skills. Many of these patient decision aids help users participate in the actual decision-making process. These tools embrace the concept of shared decisionmaking, a model of patient-centered care that enables and encourages people to play a role in the management of their own health. This model is based on the premise that consumers, armed with good information, can and will participate in the medical decision-making process by asking informed questions and expressing personal values and preferences regarding their conditions and treatment options. A leading developer of video-based shareddecision aids is the non-profit Foundation for Informed Medical Decision Making in Boston, Massachusetts (www.fimdm.org). Their videotapes (on diverse topics such as breast cancer treatment options, colorectal cancer screening alternatives, and treatment choices for coronary artery disease) can be accessed and reviewed by patients either on their own or in consultation with professional health coaches, available around the clock by phone. Other resources for shared decision-making tools are The

Cochrane Collaborative (www.cochrane.org), an international nonprofit organization supporting clinicians and consumers in making informed decisions, and the Ottawa Health Research Institute (www.ohri.ca), offering an international inventory of patient decision aids.

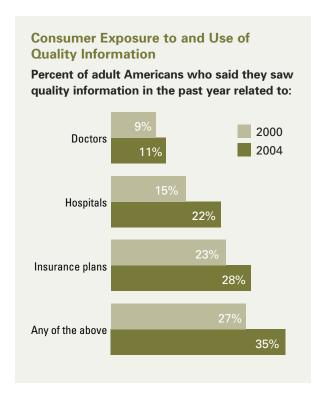
IV. Evidence Regarding Use and **Impact**

DESPITE THE RECENT PROLIFERATION OF VARIOUS TYPES of consumer decision-support tools in health care, evidence regarding their use is as yet quite limited and somewhat mixed. This section explores the impact that some of the major types of decision-support tools described earlier in this report have on consumers' health care decisions.

Health Care Report Cards

Health care report cards have become common as a decisionsupport tool, especially related to choice of health plans and hospitals. Large employers, business coalitions, government purchasers (such as Medicare and state Medicaid agencies), and major health plans are now distributing comparative reports on the quality of health plans and hospitals in an effort to provide employees and other beneficiaries with better information for making health plan and provider selection decisions. Also, national and local media organizations and nonprofits have created annual magazine reports on the quality of HMOs, hospitals, and doctors. What began a little over a decade ago with a few experiments in public disclosure of comparative performance information has grown into a new commercial industry, marked most recently by the emergence of for-profit Internet companies selling their quality information services to health plans and publishing online health plan and provider report cards on the Web.

An important monitor of the American public's awareness and use of health care quality information in decision-making is the national survey conducted every four years since 1996 by the Kaiser Family Foundation (KFF), the Agency for Healthcare Research and Quality, and the Harvard School of Public Health. While the number of people who report having seen any information at all on the quality of hospitals, health plans, or doctors remains fairly low, it increased from 27 percent to 35 percent between 2000 and 2004.7 Moreover, of those who reported seeing comparative quality information, over half said they had used it to help make a decision about their care.8



Significant controversy exists regarding the impact of public reporting of comparative performance information on consumer decision-making. The debate over effectiveness has been difficult to resolve due to the paucity of conclusive evidence. Because most studies are limited to a specific geographic area and to one or two performance measures, it is difficult to extrapolate these findings to the broader population. In addition, some studies are conducted as laboratory experiments, using hypothetical situations as opposed to evaluations of actual impact. For example, several experimental studies have found that patient survey results and other performance information can influence consumer decisions when the information is read and understood. 9,10,11,12 Results from such laboratory studies, however, may be more difficult to defend than evaluations based on actual consumer behavior.

Those studies that have examined the actual behavior of consumers, based on their use of comparative reports, have produced conflicting results. For example, a recent analysis of report cards on bypass surgery in New York found that the information had an influence on patients' choice of surgeons. 13 And a two-year follow-up study of consumers exposed to public reports on hospital quality in Wisconsin found significantly greater recall of both high- and low- performing hospitals compared to consumers who had not been exposed to the reports.¹⁴ A number of other studies, however, suggest that performance reports do not have a significant effect on consumer decisions. 15,16 Until more comprehensive and systematic evaluations are conducted that adequately reflect the impact of public reporting on consumer decision-making, the debate over their effectiveness will remain grounded in laboratory studies and anecdotes, and the controversy about them will remain.

Health Plan Decision Tools

There is some evidence to suggest that decisionsupport tools that focus on choice of health plans are being used at a substantial rate. For example, 20 percent of the employees of 14 companies that contracted with Sageo (a vendor of decision-support tools) used at least one of the firm's modeling tools to assist with plan choice.¹⁷ Also, as more consumers are offered consumer-directed health plans, about which consumers are required to make more—and more complex—decisions, they are likely to make greater use of these tools.

The limited evidence available also indicates that health plan decision tools have moderately positive impacts on knowledge about the plans, satisfaction with the decision-making process, and likelihood of considering alternatives to current plans. In particular, decision aids have been shown to help consumers select plans that better meet their specific needs and preferences. For example, tools can help those especially concerned about out-of-pocket expenses to choose plans that minimize those costs, while those concerned primarily about member satisfaction or access to a preferred provider can use such tools to help them find plans that meet those criteria. 18,19 In one major national study of health benefits and behavior, nearly two-thirds of those who used a plan comparison tool cited it as being

extremely or very important in making their annual enrollment decision; just over half felt the same way about a provider directory.²⁰ To date, there are very few studies that have examined the quality of decisions made following use of a decision-support tool; of the studies that do exist, a few have shown positive effects and a few have shown no effect, but none has shown a negative effect.²¹

For example, in a Hewitt Associates survey of employees during open enrollment, 62 percent of survey participants said that a health plan cost calculator tool helped them to consider at least one employer-sponsored health plan other than their current plan, while 32 percent said that they would likely choose a different plan as a result of information in the tool. Sixty-six percent said that a health plan comparison chart prompted them to consider a different choice, while 27 percent indicated that the tool would likely lead to them to choose a different plan.22

Decision Tools for Care and Treatment Options

The evaluation research on treatment decision aids is more extensive than on report cards and plan choice decision tools, as well as more promising in terms of impact. In a major, systematic review of treatment decision aids, researchers at the Ottawa Health Research Institute (OHRI) found that these aids significantly improved patient knowledge, increased the proportion of patients with realistic perceptions of potential benefits and harms, reduced decisional conflict and the proportion of patients who are passive in decision-making, and overall helped patients reach a decision.²³ The same study found that decision aids with more detailed information seem to have more of an impact, leading to higher levels of knowledge, more realistic expectations, and greater correlation between patient values and choice.²⁴ Similar positive effects from treatment decision-support tools were detected in an earlier study that found that in eight of nine randomized trials of interactive videodiscs, videotapes, and brochures/fact sheets, users of these aids reported

greater knowledge concerning their treatment options.²⁵

A potentially significant result from evaluations of treatment decision aids is that individuals using these tools appear to make more conservative medical decisions, in particular choosing major elective surgery and cardiac revascularization surgery less often. For example, the OHRI review found that in six of seven trials patients using a decision aid were less likely to choose major elective surgery, with reductions ranging from 21 to 44 percent;²⁶ several other studies have similarly shown that patients using decision-support tools are more likely to select non-surgical treatments. These studies also have shown that treatment information programs can increase patient compliance with treatment regimens and therefore improve health outcomes.²⁷ In combination, these studies suggest the potential for treatment decision aids and information tools to help contain costs and promote better outcomes, though the data are still far from comprehensive and much more research over a wide range of patient decisions is required.²⁸

In sum, the evidence regarding the impact of consumer decision-support tools is limited, but promising. Though decision-support tools are not yet used extensively, awareness of them among consumers is growing. The task of tool developers, and of those in the health care community who wish to make greater use of such tools, will be to recognize and overcome barriers to broader and more effective use, and to make improvements in tool design, accessibility, and dissemination—the subjects of the next two sections of this report.

V. Key Barriers to Effective Use

Although the availability of and interest in decision-support tools appears to be increasing, at least among certain segments of the population, a number of barriers stand in the way of their more widespread and effective use. Barriers exist both to the development and implementation of such tools by health plans and providers, and to their use by consumers. The following is a discussion of barriers common to decision-support tools for both plan and provider selection and treatment choice.

Lack of Consumer Awareness

While some types of information and tools are more prominent than others, overall awareness about decision-support tools remains quite limited nationally. For example, a Hewitt Associates national survey of more than 39,000 employees found that over half were unsure whether their employers provided access to data on the costs and/or quality of prescription drugs, hospitals, or physicians, and 60 percent did not know if they had online access to disease management tools, medical expense calculators, or information on rising health care costs.²⁹ The KFF/AHRQ poll cited earlier, while showing an increasing level of consumer awareness about quality information, still reported that only one-third of the adult population has seen any type of comparative report on health care quality.

Lack of Relevant and Standardized Content

A major stumbling block to effective use of decision-support tools is lack of content that is relevant and meaningful to consumers. For example, there has been a rapid growth of public reporting on the performance of health plans and hospitals, but such information on individual doctors remains relatively scarce. Measures of health care quality (such as clinical process indicators and reports on patient experience with care), once staunchly resisted by the hospital industry and organized medicine, are now fairly well-developed and readily available, but comprehensible measures of the cost of services to individual consumers remain difficult to come by. Finally, even when there is a substantial amount of available data, it is not always fully usable by consumers. A lack of standardization in measurements and reporting handicaps the consumer's ability to compare performance across providers.

Poor Design and Presentation

Regardless of the function and content of decision support, effective framing and presentation of information are critical to widespread consumer understanding and effective use. Many recent studies have found that information provided to consumers is not easily evaluated or interpreted, and consequently may confuse the consumer and create the potential to make a wrong choice. ^{30,31,32,33} Some data displays are so confusing that consumers cannot discern even substantial differences in performance, let alone identify desirable options.³⁴ And given complex and even conflicting information, consumers may even be harmed by the experience. At best they will rely on other inputs, but they may also take shortcuts or even avoid the decision altogether.³⁵ One of the most prominent examples of the potential for decisionsupport tools to confuse rather than clarify is the online support tool for the new Medicare prescription drug program (www.medicare.gov). According to an Associated Press/Ipsos poll in January 2006, most people find the new drug program tool hard to navigate, even if they are well-educated and cognitively alert.³⁶ Use of complex medical terms in treatment choice tools presents similar challenges, especially for those with literacy or language barriers.³⁷

Missing Features in Web-Based Tools

Many Web-based tools lack the functionality consumers have come to expect from the Internet. According to a 2003 Forrester Research analysis of 375 Web sites (including sites providing personalized transaction services and decision support for financial, retail, and media firms), health plan sites failed to satisfy even half of their online members, in contrast to high satisfaction scores for media and retail sites. Key complaints included inadequate content, poor navigation structures, and missing transactional capabilities.³⁸ Contributing to the lack of good design and functionality in decision-support tools is the very limited use of formative testing that has been done with consumers to evaluate what features work and what elements are absent or confusing.

Lack of Trust in the Source of Support

Even when sources of information are known and familiar—such as health plans, employers, and government agencies—many consumers do not trust them to be impartial. For example, the 2004 KFF and AHRQ poll found that 69 percent of respondents believe employers are not a good source of information about the quality of the health plans they offer because their main concern is saving the company money.³⁹ Most consumers continue to rely heavily on friends, family members, or health care providers in making health care decisions.

Low Levels of Health Literacy

Information in decision-support tools is often complex and presented at reading levels quite difficult for, if not beyond the grasp of, many consumers, and offered in ways that require far more cognitive effort than most users are willing to exert. 40 Because of this complexity, it is estimated that 90 million adults lack the skills to effectively use the information.⁴¹ The elderly have particularly high health literacy problems. In a study evaluating consumer comprehension of comparative information, Medicare beneficiaries made almost three times as many errors as nonelderly respondents.⁴² The Medicaid population also has a very limited general reading ability; the average reading level for the adult population as a whole is between eighth and ninth grade, while the average Medicaid beneficiary reads at a fifth grade level.

Lack of Online Access to Web-Based Tools

While online access is a boon to most Americans, many consumers, particularly the elderly and the poor, remain on the other side of the "digital divide," without access to the computers, connections, and skills needed to use online decision support. Even in California, where Internet use is high, there are wide disparities in access to the Internet and in computer literacy. Only 45 percent of Californians living in households with annual incomes of less than \$30,000 report having access to the Internet, compared to 77 percent of Californians with higher

incomes. Fifty-eight percent of English-speaking Latinos have access, compared to 63 percent for all Californians. And Spanish-speaking Latinos are only half as likely as their English-speaking counterparts to look for health information online.⁴³

Lack of Incentives for Clinicians

Effective use of decision support and shared decision-making requires not only engaged consumers but informed and supportive clinicians. Due to busy practices, however, often compounded by resistance to new forms and levels of patient involvement, many clinicians lack the time and/or training to engage in long discussions with patients regarding treatment options. Current reimbursement incentives reward costly procedures and hurried visits; they do not reward the kind of counseling needed to elicit patient preferences and to present detailed information regarding treatment options.⁴⁴

The effect of these barriers on the use of health care decision-support tools means that tool developers and sponsors must think strategically before embarking on their development. Developers must consider all aspects of the decision-support process, from audience and function through design to dissemination and feedback, before putting tool development in motion. Such development strategies are the subject of the following discussion.

VI. Strategies for Promoting More **Effective Use**

This section presents several strategies for addressing some of the key barriers to effective use of consumer decision-support tools. Because report cards are the most widely available tool for consumers today, and because they have been more thoroughly evaluated and tested than many of the newer tools, much of this section is drawn from research on report cards. Most of the strategies derived from this research, however, are generally applicable to other types of decision-support tools as well. Additional resources are noted at the end of this section.

Understanding the Decision Context and Audience

Tools must be designed to meet the decision context—that is, the needs, preferences, and specific circumstances of potential users. The most appropriate content, design, marketing, and distribution of decision-support tools, including comparative performance reports, will vary depending upon the nature, frequency, and complexity of the decision being supported, the degree of real or perceived choice available, and the factors that are most important to consumers who make these choices.

Developers of tools need to take steps during the planning process to understand the environment in which decisions will be made, as well as the needs and preferences of the intended audience. Tools developed without this advance planning may end up being of little or no value to the intended end user. Key questions include the following:

- What decision is the tool intended to support? Design, content, format, and delivery all may vary depending upon the specific decision to be made, e.g., selection of a health plan, choice of provider, election of treatment.
- How is the decision made? Tool developers need to consider the circumstances under which people make a decision, the urgency of the decision, and the frequency of the decision—all of which influence the kind of information provided and the methods of delivery.

- How many choices do potential users have? For example, a health plan selection tool designed to assist employees in choosing between a handful of employer-sponsored plans will be different from one designed to assist all federal employees with their myriad plan options. A simple, paper-based tool may be appropriate for the former, while an interactive, computer-based tool may be needed for the latter.
- Who is the intended user for the tool? What are the characteristics of the intended audience (e.g., age, demographics, language skills, computer access and skills, cultural background)? Audience characteristics may influence how information should be presented, for instance, whether data should be distilled into a brochure or provided in multiple pages of detailed tables. Audience characteristics may also determine the channels through which the information is to be delivered; some audiences respond best to familiar community-based organizations, while others are more comfortable with impersonal vehicles such as Web sites. Perhaps most importantly, tool developers must try to gauge whether the intended audience is likely to be receptive to this particular kind of tool for the given decision. If not, the tool might be better focused on secondary audiences (e.g., physicians or adult children of elderly beneficiaries) who can influence the actual decisionmaker.
- What are the health-related needs, concerns, and interests of the intended audience? The tool must address the information needs of the target user. At a minimum, this requires examination of existing research regarding the needs of audiences with similar characteristics and decisions to make. Ideally, an understanding of the target audience's needs and concerns would result from direct interaction with actual potential users, through focus groups or one-on-one interviews.

The Critical Role of Testing

Consumer testing—particularly focus groups and individual interviews with potential users—can play a major role in ensuring that a decisionsupport tool satisfies a real need. In the initial stages of the development process, testing can help tool developers learn what consumers really care about and what information they need to make better decisions. During the process of developing content, data displays, and interactive features, testing can also provide insights into whether consumers can understand and use the information as it was intended.

Testing also often uncovers inconsistencies between what people say they are interested in and what they actually care about. For example, a series of focus groups in one study found that although consumers said they were interested in seeing an emphasis on preventive care in health plan reports, they responded more intensely to risk-related information, such as messages about negative outcomes.45

Crafting Appropriate Content

While the appropriate content for a tool will vary according to many factors (the decision being supported, characteristics of the intended audience, the available data, etc.), research suggests that certain kinds of information should be included in any decision-support tool:

- **Explain the purpose.** The purpose of the tool and how the tool works should be explained clearly and concisely before the potential user is required to negotiate the information itself. Introductory material should allow users to decide whether the tool is relevant to them and worthwhile to use.46
- Provide a compelling motivational message. While the value of the tool may seem obvious to the developer, the target audience may not immediately appreciate what it offers them. Research with consumers suggests that the framing of the message can play a major role in determining the effectiveness of the message in the tool itself. See the following box to learn more.

How to Frame Use of a **Decision-Support Tool**

The use of a decision-support tool may be framed as a way to avoid risk (a loss frame) or a way to improve health (a gain frame). The evidence suggests that framing a decision-support tool as a way to avoid risk (e.g., the risk of getting a disease or experiencing a bad outcome) is more likely to capture an individual's attention and encourage him or her to process information than framing it as a way to realize gains (e.g., having better health). Moreover, in one study those with higher incomes were more willing to pay extra for a higher quality health plan when presented with the risk message (as opposed to the gain message).47

Some researchers have concluded that loss frames are more effective with respect to decisions about screening, treatment choice, and plan selection, while gain frames are more effective with choices related to prevention.⁴⁸ However, in some instances risk messages may also be more effective with respect to prevention. For example, a recent study found that a loss-frame message had more effect than a gain-frame message in encouraging HIV-positive people to take preventive steps to avoid unsafe sex.49 The loss frame also seems to improve comprehension, as consumers exposed to this framework were more likely to correctly answer questions about comparison charts and health plan rules and restrictions than were those exposed to a more positive frame.50

Reference the familiar. It is often helpful to link potentially unfamiliar information in the tool with important factors that are familiar. For example, a tool designed to assist consumers in choosing a medical group or specific practice site should incorporate some discussion of the familiar subjects of location, hours of operation, medical specialties available on site, and other services, such as pharmacy and parking. Weaving such familiar information together with less familiar information on quality, as measured through patient survey results or clinical indicators, can engage the audience to consider the less familiar factors. A study of consumer responses to a report card comparing health care systems in Minnesota

- revealed that such descriptive information was valued as much as the quality measures presented, and it helped create a context for learning about comparative quality differences.⁵¹
- Emphasize what is most salient to the intended audience. The content of the decisionsupport tool should be tailored to the intended audience; different types of consumers may find different kinds of information relevant. For example, with respect to information on quality performance, a generally healthy consumer choosing a health plan or a provider may be more interested in the interpersonal and structural aspects of care (communication, timeliness, responsiveness, ease of access) than in clinical or physiologic outcomes.⁵² Consumers who are in ill health may be more interested in other aspects of quality, such as mortality rates and quality-of-life outcomes. People with mobility impairment have different quality-related concerns than the general population, such as handicap access,⁵³ and thus they too require different information.
- Explain complicated information. Clear explanations are needed to help people interpret statistical or technical information. In the context of quality indicators, tools should include an explanation of why performance on a particular indicator is a good measure of quality, and whether a high or low rate is desirable and why.⁵⁴ For example, use of physicians specially trained in hospital intensive care as a measure of patient safety (one of the Leapfrog Group's safety measures) is an unfamiliar concept for most people. Testing with potential users is an effective and efficient way to identify terms that users may not understand. Rather than using and then having to define those terms (e.g., in footnotes or glossaries), tool developers should strive to replace them with terms that are understandable to the user.

In the context of treatment options, it may not be appropriate or even possible to say whether or not an option is desirable, but the tool should at least explain in direct, simple language what

the technical information means for the user. For example, rather than simply citing research studies on the statistical likelihood of certain outcomes from alternative treatments, a decision-support tool might present an overview of possible outcomes along with the perspective of patients who describe their experiences and outcomes with the different treatments so users can better relate to the choices they have to make.

Strategies for Presenting **Complex Information**

Developers of decision-support tools need to present information in ways that allow users to easily access pertinent material, understand key messages and implications, and make comparisons of relevant options. The following strategies can help achieve this goal:

Break down decisions into discrete steps.

Because consumers have difficulty processing multiple pieces of information at the same time, the decision process and the information needed to support it should be divided into manageable steps.

For example, the process of choosing a health plan can be broken down into the following steps:

- Determine which health insurance options are relevant to the particular user;
- Estimate future health costs;
- Systematically compare the costs and benefits of several options;
- Choose the plans within those options that best fit the user's needs; and
- Choose the best plan from among the smaller set of previously narrowed choices.

In one study, a series of worksheets were used to help users compare and narrow their health plan options based on one factor at a time, with a summary worksheet at the end helping users pull together their key results from each of the previous worksheets. Testing found that every user

- was able to complete each worksheet and all but one was able to identify a preferred plan. Users unanimously agreed that they would use the tool if it were sent to their home.⁵⁵
- Simplify difficult tradeoffs. Consumers may find it difficult to evaluate certain tradeoffs, such as out-of-pocket costs versus quality, particularly when there may be wide variations across potential choices. Decision-support tools can help to simplify or even eliminate these potential tradeoffs. For example, instead of presenting cost and performance information separately, performance information could be presented within cost strata.⁵⁶ In some cases, integrating different kinds of information can help users see that they may not actually have to make anticipated tradeoffs, that is, that high quality performance is available among low-cost plans or providers.
- Make navigation easy. A variety of navigational aids can help guide users throughout the material. On Web sites, navigation can be optimized by having a clear and logical structure, making all major elements of the site accessible from any page, avoiding dead links within the site, and including a self-contained title on each page.⁵⁷ In printed materials, tables of contents and visual cues, such as boxes or arrows at the bottom of the page, can help the user see how different pieces of information link together. Testing of these cues found that they facilitated a user's ability to work through materials and pay attention to and absorb key messages.⁵⁸
- Make it easy to find key messages. Long sections of dense text should be avoided, as users may miss key points. Whether on the Web or on paper, more information is not necessarily better. Simple figures and headings that highlight key messages and facilitate skimming can communicate more effectively. Testing has shown that a simple table highlighting key differences between types of plans improved comprehension

- of these differences.⁵⁹ Text format can also be important: judicious use of bulleted lists, font styles (e.g., putting key messages in bold type), colors, and white space can contribute to making information more accessible to consumers. 60,61
- Make information easy to evaluate. Information should be formatted in a way that helps the user sort out options, make comparisons, and draw conclusions. Using symbols rather than (or in addition to) numbers, summary tables, color coding, and exemplary stories are all examples of ways to make information easier to evaluate.
 - Research has found that information presented in these ways is more likely to be used effectively.⁶² For example, consumers have been found to place greater weight on quality information, and to have better comprehension of it, when the information is presented using stars or other visual cues and/or is ordered by performance. 63,64 Making information easy to evaluate has also been shown to have an impact with other types of purchasing decisions outside of health care. For example, a study found that consumers are much more likely to buy lower-priced products when unit pricing is displayed in a single chart with products ordered from least to most expensive. Simply posting the per-unit price next to each item (as is done today in most grocery stores) does not yield a change in purchasing patterns.⁶⁵
- **Layer information.** Putting general information early (in a written tool) or at higher levels (in a Web-based tool), with more detailed information later or at lower levels, can help meet the needs of consumers with different characteristics (e.g., education, literacy level, interest, etc.). Some users may be more interested than others in technical or statistical information. Cognitive testing of a written tool showed that developers can safely place this kind of information in the back of the report, allowing those who are not interested to ignore it and those who are interested to find and use the material.66

■ Use categories or frameworks to present complex information. Because individuals can only process a limited amount of information at a time, performance information should be grouped into easily understood categories. (As noted above, more detailed performance information on individual measures can be presented later (in a written report) or at a lower level (in a Web- or computer-based tool). An example is the Institute of Medicine quality framework, which defines quality in six categories intended for easy interpretation by consumers: safety, efficiency, patient-centeredness, effectiveness, timeliness, and equity. A focus group study found that a modified version of the IOM framework, broken down into three categories, enabled consumers to expand their understanding of health care quality and to value measures of quality that they might not otherwise have considered important.⁶⁷

Selecting an Appropriate Medium

The appropriate medium for a decision-support tool depends upon the needs, characteristics, and preferences of the intended users of the tool, on the nature of the decision being made, and on the number of choices to be considered.

- Simple media for simple choices. Relatively simple choices, such as choosing among a few health plans or between two treatment options, are likely best supported through relatively easy-to-use, low-tech media, such as printed information/worksheets or videos. Videos are also a useful way to help decision-makers visualize their options and hear from other consumers who have faced a similar decision. These low-tech approaches are particularly useful for would-be users who lack access to computers and/or the skills to use them.
- Technology can make complex information accessible. Where choices are more plentiful, decisions more complex, and tradeoffs less clear, higher-technology media such as interactive CD-ROMs or Web sites may be more appropriate. These tools can allow users to navigate to the

material that is most relevant to them. For example, Web-based tools supporting consumerdirected health plans can greatly simplify the complex tradeoffs between different levels of deductibles, coinsurance, and premiums in these plans. However, the information must be explicitly tailored to the medium: transplanting material from printed versions to computer, or vice versa, without suitable modification is rarely successful.

Achieving the right level of interactivity. While computer-based tools allow for interactivity, high levels of interaction are not always a benefit to the user. For example, the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Consortium found that more interactivity increases the cognitive burden of using a Webbased report of survey results. To overcome this, researchers revised their tool to reduce the levels of and choices for information on the site; they also added a navigational bar throughout the site.⁶⁸

Interactivity can have advantages as well, to the extent it fosters greater involvement and allows users to tailor information to their preferences. Thus, a balancing act is necessary in creating interactive tools—that is, the tool must provide enough interactivity to confer its advantages without overburdening users. Finding this right balance for a given tool is made considerably easier through careful testing with users.

Coupling information and tools with personal counseling. Although well-designed decision aids can confer many benefits, the role of personal human guidance cannot be replaced and should not be underestimated. In some cases, decision aids have been shown to have no effect at all unless they are combined with direct personal counseling (in particular, to clarify values).⁶⁹ Some observers believe that the benefits patients obtain through human involvement in decision support are less about the knowledge gained than the value of the interaction and relationships that such counseling engenders. Various approaches

can be used to bring counseling into the decisionmaking process, such as training clinicians in the requisite skills or using third-party decision counselors to fulfill this function. Regardless of the specific approach, the important element is providing the human factor as an integral complement to the process.

Maximizing Awareness and Use of the Tool

Marketing and distribution of a decision-support tool can go a long way in determining whether and how it is used. There are three critical aspects to successful marketing and distribution: promoting the availability of a tool, building credibility with the end user, and ensuring that the tool is available at the time it is needed.

Promoting Tool Availability

Since many consumers are unaware of the availability of decision-support tools, the first promotional task is to let potential users know about the tool through an effective and well-targeted outreach program.

Repeated exposure to tools such as quality reports (e.g., educational campaigns highlighting their value) has been shown to increase awareness and perceived value of the tool.⁷⁰ In fact, use of decision-support tools appears to directly correlate with frequency and type of communications about the tool. For example, there were great differences among the five companies using the Pacific Business Group on Health's "Health Plan Chooser," a Web-based health plan selection tool, in the number of directto-employee communications about the tool. The company that did the most (seven communications) had the highest use rates for the tool, while the company that did the least (one communication) had the lowest use rate. A similar linkage was found regarding email communications to employees (the emails included links to the tool); the company that did the most (four, including two that were only about Health Plan Chooser) had the highest usage rate.71

There are a variety of ways in which the availability of decision-support tools can be marketed to potential end users.

- Internal communications. Customer support, such as telephone hot lines, Internet chat rooms, or worksite resources developed and maintained by the tool sponsor, may help make consumers aware of tools and thus encourage their use; these support services also help consumers to interpret the information available through the tools.⁷²
- External media. The health care and general media may be employed as marketing vehicles. Sponsors of decision-support tools can work with the media to give them the "news" value when tools (e.g., comparative performance information) are first released.⁷³ Media coverage of report cards or other decision-support tools might also make use of "human interest" stories, particularly negative stories of patients who have suffered injury that might be avoided by consumers who properly use information offered in the tool.⁷⁴
- Participation requirements. Another strategy for increasing awareness and use of tools is to require consumers to make a decision that can be supported by an available tool. For example, some companies require their employees to make a health plan selection each year—even if that decision is to remain with their existing plan—rather than allowing them to stay with the plan by default. Being forced to make a decision may encourage some consumers to use a decisionsupport tool to reconsider their options. Some organizations with Web-based tools also require employees to enroll online, thus increasing the likelihood that they will see and use the tool. In this way, mandatory online enrollment yielded higher use rates of the PBGH Health Plan Chooser tool among those individuals who were switching plans. The two companies that required all enrollment to be completed online found that more plan-switching employees used the tool.⁷⁵

Building Credibility with the End User

Even consumers who are aware of a tool may not use it if they do not find it to be credible, objective, and trustworthy. There are several strategies that tool developers can employ to establish a level of trust with users.

- Creating a brand image. One strategy for building credibility is to create a brand image that will make the tool recognizable and acceptable to potential users. In the context of decisionsupport tools, one of the best examples of a trusted brand is Consumers Union, publisher of Consumer Reports, which is known for its objective evaluations of products and services and its freedom from outside influence. However, unless a tool sponsor already has a reputation with potential users, it can take some time to establish a brand image that will appeal to the target audience. One way around this problem is for a tool sponsor to team up with an entity that already has a brand image that resonates with the sponsor's audiences, such as a respected academic institution or other non-profit organization.
- Leveraging existing relationships. In some cases, credibility and trust are inherent in the relationships that people have with certain individuals (such as personal physicians) or organizations (such as religious institutions and cultural associations). Tool developers can benefit from such relationships by forming partnerships with these individuals and organizations to become channels for delivering tools to the target audience. In this way, the trusted individuals or organizations offer implicit reassurance to users of the tools.

Making the Tool Available When Needed

An important strategy for encouraging use is making sure that consumers have access to the tool at the point in time when they actually need it—that is, when they will be making a decision. Studies have shown that there are certain "teachable moments" when consumers are most likely to need support, such as when they:

- Choose a health plan (e.g. during open enrollment, upon a job change);76
- Choose a new physician or group practice (e.g. when they move to a new location, change health plans, or a physician retires);
- Become pregnant;
- Turn 65 and become eligible for Medicare;
- Leave a hospital after an inpatient stay;
- Are diagnosed with a serious medical condition; and
- Require a major procedure, new medication, or new treatment.77,78

To enhance tool availability, developers should consider when (e.g. choosing a plan, facing a new treatment) and where (e.g. at home, at work, in the doctor's office) people are most likely to use it, and design the tool to suit that need. For example, if the user is likely to need time and privacy to use the tool effectively, a CD-ROM that a doctor can send home with a patient would be more useful and appropriate than a kiosk-based tool that can only be viewed in a waiting room.

VII. Conclusion

As consumers assume a greater role in health care decision-making, it will become increasingly important to provide them with the information and tools they need to clarify choices and make informed decisions. While various types and forms of decision-support tools have emerged in recent years to begin addressing this need, significant barriers remain to their widespread and effective use. Evidence regarding the use and impact of decision-support tools is only beginning to emerge, but experience with early adopters suggests some promising, practical steps to improve the design, content, format, and dissemination of tools that can be taken by tool developers to substantially increase use and effectiveness.

As described in this report, many of the recommended tool improvements are not difficult to make technically, but will require a commitment of time and resources. In some cases, improving the effectiveness of decision-support tools will also require significant political will, since empowering consumers to make truly informed decisions about their medical care may threaten the long established balance of power and influence between patients and physicians. Moreover, presenting easy-to-understand performance and cost comparisons among doctors, hospitals, and other health care providers is likely to engender resistance by at least some in the health care industry. Finally, as noted, some barriers are systemic in nature, related to reimbursement systems that have yet to recognize and value the time and training it takes for health care practitioners to fully engage as supportive partners with their patients in the decision-making process.

If consumers are being asked to take greater responsibility for choosing their care, they must have the appropriate tools to make fully informed decisions. It is incumbent upon the developers of health care decision-support tools to arm themselves with the most current information about what makes tools most effective and useful to the consumers who need them.

Appendix: Additional Decision-Support Resources

Plan and Provider Choice

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Care and Treatment Choice

- Foundation for Informed Medical Decision Making (www.fimdm.org): Since 1989, the Foundation has produced tools, including videotapes and Web-based decision aids, with information that can help patients make an informed decision about some of the most common and important medical conditions: coronary artery disease, prostate cancer, breast cancer, back pain, osteoarthritis, benign uterine conditions and benign prostatic hyperplasia.
- Ottawa Health Research Institute (www.ohri.ca): This site offers an inventory of international patient decision aids, including many of the existing shared decision making programs, evaluations of those programs, and information about how to obtain them.
- The Cochrane Collaboration (www.cochrane.org): This international non-profit organization produces and disseminates systematic reviews of healthcare interventions and promotes the search for evidence in the form of clinical trials and other studies of interventions. The major product of the Collaboration is the Cochrane Database of Systematic Reviews, published quarterly as part of The Cochrane Library, a collection of evidence-based medicine databases.

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